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The English Patient

Leslie Burke wants to live; the National Health Service has a second opinion.
by Wesley J. Smith

London

THE MOST IMPORTANT BIOETHICS LITIGATION in the world today involves a 45-year-old Englishman, Leslie Burke. He isn't asking for very much. Burke has a progressive neurological disease that may one day deprive him of the ability to swallow. If that happens, Burke wants to receive food and water through a tube. Knowing that Britain's National Health Service (NHS) rations care, Burke sued to ensure that he will not be forced to endure death by dehydration against his wishes.

Burke's lawsuit is even more important to the future of medical ethics than was the Terri Schiavo case. Schiavo was dehydrated to death--a bitter and profound injustice--because Judge George W. Greer ruled both that Terri was in a persistent vegetative state and (based on statements she allegedly made during casual conversations some 20 years ago) that she would not want to live under such circumstances. In other words, Terri Schiavo lost her life in order to safeguard her personal autonomy, though she never made the actual decision to die.

But Burke, who is fully competent, worries that his wishes will be ignored precisely *because* he wants food and water even if he becomes totally paralyzed. Receiving food and water when it is wanted certainly seems the least each of us should be able to expect. But, it turns out, whether Burke lives or dies by dehydration may not be up to him. According to National Health Service treatment guidelines, doctors, rather than patients or their families, have the final say about providing or withholding care.

Burke won his case at the trial court level when a judge ruled that denying the tube-supplied food and water a patient wants "would be a breach of claimant's rights under . . . the European Convention on Human Rights." This should be uncontroversial. But the General Medical Council, the medical licensing authority, appealed, joined by the British government.

Why do Britain's medical establishment and government insist that Burke be denied a right to decide whether he receives tube-supplied food and water? It all boils down to two concepts that are increasingly intertwined in modern bioethics theory and practice. First is the so-called quality-of-life ethic that presumes to judge the worth of patients' lives according to their mental and physical capacities. Under this view, doctors or bioethicists may judge a life to be of such low quality that it is not worth extending, irrespective of the patient's wishes. The second issue is money--an especially potent factor for England's increasingly strained socialized medical system.

Accordingly, the secretary of state for health argued before the Court of Appeal that while patients have the right to refuse life-sustaining treatment, they don't have a corresponding right to receive it. Even though the Burke case does not involve high tech medical procedures--he is not asking for a respirator or kidney dialysis, after all--the government claims that the trial court's ruling undermines the authority of doctors to make the "clinical judgment" about whether a patient's "treatment would be of benefit," based at least in part on the question of "the resources which are available." The right of doctors to exercise such control is "absolutely fundamental to the day-to-day functioning of the NHS."

In support of the government's position, the secretary of state filed a statement by Elizabeth Woodeson, the head of scientific development and bioethics at the Department of Health. Her testimony demonstrates the threat that contemporary bioethics poses to the lives of vulnerable patients. As Woodeson explained, the National Health Service established the National Institute for Health and Clinical Excellence (given the creepily inappropriate acronym NICE) to issue "clinical guidelines" that blend efficacy of outcomes, quality of life judgments, and economics:

An assessment is made of the cost of the treatment per additional year of life which it brings, and per quality adjusted life year (QALY) . . . which takes into consideration the quality of life of the patient during any additional time for which their life will be prolonged. The clinical and cost effectiveness of the treatment under review is then used as the basis for a recommendation as to whether or not . . . the treatment should be provided in the NHS. . . . The Secretary of State believes that . . . clinicians should be able to follow NICE guidelines without being obliged to accede to patient demands. . . . If that principle were undermined, there would be considerable risk of inefficient use of NHS resources.

In other words, medical care is effectively rationed by the National Health Service under guidelines set by bioethicists based on their beliefs about the low quality of life of patients whom they have never met. While the views of patients and families are to be taken into account when deciding whether to provide treatment, they are not determinative.

This top-down approach is what Leslie Burke is rebelling against. He knows that many bioethicists have a low opinion of the quality of life of people with profound disabilities. Burke doesn't trust doctors, much less bioethicists, to judge whether his life is worth living. "I feel strongly that my body and my being are mine," Burke insisted when I visited him recently at his Lancaster home. "But my desire [to live] can be overridden" based on prejudice against the disabled. "I am no different than anybody else, but I am not seen that way anymore."

Adding heft to Burke's concerns: When I privately discussed his case with a prominent British physician who I expected would sympathize with Burke's views, I was taken aback when he told me crossly, "Burke is only thinking of himself rather than looking at the bigger picture." How thoughtless of him.

IT WOULD BE A MISTAKE to assume that Americans are safe from having life-sustaining treatment rationed like this just because we don't have a national health service. Burke is fighting a broader movement in the bioethics field, "Futile Care Theory," that is also gaining traction here. Futile care theory is a one-way street when it comes to patient autonomy and end-of-life care. Futilitarians assert that patients have an absolute right to refuse life-sustaining treatment but are not similarly entitled to insist that their lives be maintained. Indeed, under futile care theory, as under the NHS rationing approach, whether a seriously ill or disabled patient's request to be kept alive is granted depends on whether doctors and bioethicists see the patient's life as worth living and spending medical resources to sustain.

For the last several years American hospitals have been quietly promulgating futile care protocols that empower their ethics committees to authorize doctors to unilaterally refuse wanted care. These futile care policies are beginning to be imposed on unwilling patients and their families.

As is usually the case in such matters, the first victims are on the far margins. Thus, in Houston, Sun Hudson, a 5-month-old infant born with a terminal disability, was taken off a ventilator in March over his mother's objections based on a Texas law that defers to futile care theory. Under the law, once a hospital bioethics committee determines that the treatment should not be rendered, the patient or family has a mere 10 days to transfer the patient's care to another hospital. This can prove difficult in this era of managed care and HMOs, since the affected patients are usually the most expensive to treat. After 10 days without a transfer, the outcome is usually death following the unilateral withdrawal of treatment--as occurred in Sun Hudson's case.

In another Houston case, one with ironic echoes of Terri Schiavo, the wife of Spiro Nikolouzos *wants* tube-feeding for her persistently unconscious husband, based on his previously stated desire to live. But unlike Schiavo's, Nikolouzos's personal wishes are not deemed determinative: A hospital ethics committee voted to refuse to continue his tube-supplied food and water and ventilator support. He would have died, but a San Antonio hospital unexpectedly agreed to provide the care. Then its ethics committee also decided to cut off care, but Nikolouzos was transferred to a nursing home. For the moment, Nikolouzos is being allowed to stay alive. But the final decision about the matter isn't his wife's: Under utilitarian Texas law, it belongs to committees of bioethicists and doctors.

In this darkening atmosphere, the Leslie Burke case could not be more important. If Burke loses on appeal, patients in Britain will be stripped of the basic human right to receive food and water through a feeding tube. Such a ruling should send a cold shiver through disabled, elderly, and dying patients everywhere.

Moreover, given the increasing propensity of some Supreme Court justices to look overseas when deciding issues of American law, a Burke loss could plausibly end up reinforcing futile care laws in this country. There will undoubtedly be protracted litigation on this issue in coming years. How Leslie Burke fares may determine whether futile care theory is allowed to metamorphose from ad hoc health care rationing into an explicit--and expanding--duty to die.

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